

Conversely where the patient did not wish cardiopulmonary resuscitation 50% of proxies failed to accurately predict this.⁹

Several respondents in our study stated that they knew the patient's wishes despite no discussion of them. Their belief was often based on the length of time that they had known or been married to their loved one. Although this was not investigated any further in our study, Sulmasy found no correlation between the time spent together and the accuracy with which a proxy could predict a person's wishes.¹⁰

In another study, Sulmasy demonstrated that a surrogate would generally choose for a patient what they would choose for themselves. This was usually the same as the patient's preference.¹¹ Not surprisingly the accuracy of a substituted judgement is better when there has been explicit discussion between the patient and proxy. In Sulmasy's study of patients with terminal diagnoses 63% had spoken to someone about end of life issues, 33% had an advance directive, and 31% a durable power of attorney for health care (analogous to the welfare power of attorney).

The success of the Act will be determined by how well the care of incapacitated adults is improved. Although knowledge of the changes in the law were poor, the implications for this in practice are more important. The role that relatives, or next of kin, play has become more central to the care of the incapacitated. It is, therefore, more important than ever that people ensure their wishes are known in advance of becoming mentally incapacitated for any reason (for sources of information see Appendix 2 at <http://www.jmedethics.com/supplemental>). The implication of not making their wishes known is that their values and aspirations cannot be taken into account when decisions need to be made on their behalf.

The evidence from the studies discussed above is that good communication is needed. The poor correlation between the subjects' desires and the predictions made by the proxies reinforce this.

CONCLUSION

The law pertaining to the care of incapacitated adults has changed in Scotland. These changes are going to have widespread effects on how the incapacitated are cared for. From this study it would appear that there is a lack of public awareness about these changes and their implications. Such information is hard to obtain and there is a general lack of study in this area. More public education is required and people should be encouraged to discuss and record their preferences for life sustaining therapy with their relatives in advance of becoming ill. One way of doing this might be by encouraging people to appoint a welfare power of attorney as this requires the granter and the potential welfare attorney to discuss the granter's wishes. An alternative approach might be to encourage the more widespread use of advanced directives, especially for known disease processes such as dementia.

The effectiveness of the Act at improving the care of the mentally incapacitated adult will depend largely on how successful it is at encouraging communication and decision making in advance of incapacity occurring.

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COMMENTARY

A worrying anomaly arose in English law some forty years ago which has never been remedied, namely, that no one—not even a court of law—can consent or refuse on behalf of an incompetent adult. The response of the English courts has been to turn to the practice of “declaring” the lawfulness (or otherwise) of particular courses of conduct—such as medical interventions or withdrawals of treatment—relating to such individuals. This has been, however, a heavy burden for the judicial system to bear, especially since the decision making authority of the medical profession has come under increased scrutiny in recent years. Scotland, for its part, was unaffected by such matters. Instead, it was challenged by an anachronistic system which permitted the court appointment of proxy decision makers, but this was cumbersome and rarely used. The Adults with Incapacity (Scotland) Act 2000 did away with this system to institute a contemporary model of proxy decision making, which places primary authority squarely with the medical profession. This can only be usurped by the specific appointment of a decisional guardian, such as a relative, but even then the rights of such a person are restricted. There is—for example no “right to refuse” on behalf of the patient. Where there are disputes the further appointment of a medical arbiter must be sought and continued disagreement will be resolved by the courts. Interestingly, the Scottish legislation has rejected the use of the best interests test as a measure of legitimate interventions on incapacitated patients. This test remains the legal standard in England and Wales. It is to be contrasted with the substituted judgment test, whereby a proxy is charged with the task of taking the decision that the incapacitated person would have taken were s/he able to do so. Despite being widely used in the United States, this test has never gained legal authority in either England and Wales or Scotland. There is, however, now more scope in Scotland to consider previous declarations by an incapacitated adult as to their later medical treatment; indeed, there is an obligation to take such declarations into account. Although similar latitude is available in England and Wales if competent advance directives have been made, these may more easily be curtailed through the application of the essentially paternalistic best interests test.

Most recently, on 17 June 2004, the Mental Capacity Bill 2004 was introduced to the Westminster Parliament in respect of reforms in England and Wales. This mirrors the Scottish framework in many ways but contains important differences. For example, there is now provision for persons, before becoming incapacitated, to appoint a donee with the power to take decisions about their welfare, property, or other specified matters once incapacity arises. This power, however, is still tempered by the best interests criterion, which the government claims builds on the common law, while offering more precise guidance. This includes an obligation to involve the incapacitated individual in each decision in as far as is possible, and to have regard to the past and present wishes and feelings of the person. Furthermore, and unlike their Scottish counterparts, donees can give or refuse consent on behalf of the

incapacitated person. This power does not extend to refusing life sustaining treatment unless the lasting power of attorney appointing the donee contains an express provision to this effect. In the absence of a nominated donee, an English or Welsh court would be able to take decisions on behalf of incapacitated person or appoint deputies to do so, constrained in each case by the parameters of the best interests test as stated in the legislation. It should be stressed, however, that this Bill is at an early stage and it has already provoked considerable controversy. Its successful passage through the legislative process is therefore far from guaranteed.

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